



Hypertrophic Cardiomyopathy Association

February 27, 2009

Committee on Public Health
RE: *Bill No. 981*

Dear Committee Members:

The Hypertrophic Cardiomyopathy Association is in support of the passage of Bill 981 which will provide for the availability of automatic external defibrillators in schools.

Hypertrophic cardiomyopathy is the leading cause of sudden cardiac arrest, SCA, in the young accounting for over 36% of deaths on the athletic playing field in the USA¹. Nationwide over 600,000 people have HCM, 7,000 reside in the State of Connecticut². These individuals can be found daily on your school campuses and include your students, faculty, parents, and visitors unfortunately only a small percentage know they have HCM. HCM is cardiology's great masquerader as its signs and symptoms are often misinterpreted as inconsequential or misdiagnosed as other disorders including athletically induced asthma, innocent heart murmur, panic attacks or mitral valve prolapse³. Symptoms of HCM can include shortness of breath, palpitations, chest pain/discomfort, lightheadedness, fainting, nearly fainting, fatigue and in some cases the first "symptom" can be sudden cardiac arrest¹.

I am sure that the American Heart Association, The Red Cross and others have provided you with the startling statistics about sudden cardiac arrest in the general public including that each day 1000 people with die from SCA. The HCMA firmly stands behind the data presented by these fine organizations. We do wish to emphasize that then those who die from SCA under the age of 40 will most commonly have HCM. In a school population that makes HCM public enemy number one in terms of sudden cardiac arrest risk. In cases of undiagnosed HCM sudden cardiac arrest may be the first identifiable "symptom" and its only treatment is prompt defibrillation – without it in fewer than 4-5 minutes the outcome will be death⁴⁻⁵.

There are other states with wonderful AED legislation that may prove beneficial to the State of Connecticut. Specifically the language used by Illinois regarding maintenance of the device is particularly well crafted, it states:

(410 ILCS 4/20)

Maintenance; oversight. (a) A person acquiring an automated external defibrillator shall take reasonable measures to ensure that: (1) Blank (2) the automated external defibrillator is maintained and tested according to the manufacturer's guidelines

You may wish to include this language in your legislation to help to ensure that once placed devices are well maintained and available for use as recommended by the manufactures.

The HCMA would also encourage the committee to include language that would hold harmless a "good Samaritan" who uses an AED in emergency situation regardless of there formal participation in a training program. Today's AED devices are so user friendly that nearly anyone can safely operate a device and save a life. As much as we would like to believe that all Americans would have formal CPR-D training the truth is few do, thus clear language protecting all by-standers will increase time to shock and improve outcomes.

HCMA

After the passage of this legislation it is important that each school have a strong Emergency Action Plans EAP's must be in place and the HCMA would suggest the committee draft a "best practices" sample to assist schools by ensuring they have comprehensive programs.

While we believe this legislation is a great step forward and fully support it, when economic situations improve we would hope the State would provide funding for AED's as well as encourage multiple devices for schools with traveling sports programs and/or larger campuses.



The HCMA represents over 4300 families, nearly 100 of them live in Connecticut including the Gingery Family of Bristol – their son Tyler testified here last year. Tyler passed away on December 2, 2008 at the age of 5 from sudden cardiac arrest in his sleep. It would be a fitting tribute to Tyler's life to see this bill passed this year. Please let Tyler bring a second chance at life to someone else.

Should any member of the committee have additional questions please do not hesitate to contact the HCMA or visit our website at www.4hcm.org

Thank you for your time and attention.

Sincerely,

Lisa Salberg
CEO/Founder

Citations:

1. American College of Cardiology/European Society of Cardiology clinical expert consensus document on hypertrophic cardiomyopathy. A report of the American College of Cardiology Foundation Task Force on Clinical Expert Consensus Documents and the European Society of Cardiology Committee for Practice Guidelines.
Maron BJ, McKenna WJ, Danielson GK, Kappenberger LJ, Kuhn HJ, Seidman CE, Shah PM, Spencer WH 3rd, Spirito P, Ten Cate FJ, Wigle ED; Task Force on Clinical Expert Consensus Documents. American College of Cardiology; Committee for Practice Guidelines. European Society of Cardiology.
J Am Coll Cardiol. 2003 Nov 5;42(9):1687-713.
2. Sudden Deaths in Young Competitive Athletes. Analysis of 1866 Deaths in the United States, 1980-2006.
Maron BJ, Doerer JJ, Haas TS, Tierney DM, Mueller FO.
Circulation. 2009 Feb 16
3. Hypertrophic Cardiomyopathy Association database of 4300 unrelated families with HCM – pending publication
4. Sudden cardiac arrest in intercollegiate athletes: detailed analysis and outcomes of resuscitation in nine cases.
Drezner JA, Rogers KJ.
Heart Rhythm. 2006 Jul;3(7):755-9. Epub 2006 Mar 28.
5. Use of automated external defibrillators at NCAA Division I universities.
Drezner JA, Rogers KJ, Zimmer RR, Sennett BJ.
Med Sci Sports Exerc. 2005 Sep;37(9):1487-92.

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